2021-22
DATA AT A GLANCE:
FAMILY SURVEYS

Selected Findings from National Core Indicators® Intellectual and Developmental Disabilities
Adult Family Survey, Family Guardian Survey, and Child Family Survey
FAMILY SURVEYS: OVERVIEW

INTRODUCTION

The 2021-22 Data at a Glance: Family Surveys shows selected findings from National Core Indicators’ Intellectual and Developmental Disabilities (NCI-IDD) suite of family surveys: the Adult Family Survey (AFS), Family Guardian Survey (FGS), and Child Family Survey (CFS).

While reviewing this resource it is important to note the following:

- “Family member” refers to children or adults with intellectual or developmental disabilities who use long-term services and supports.
- “Respondent” refers to family members or guardians of the person using services.
- Data displayed in this resource reflect a selection of key outcomes. Please refer to the AFS, CFS, and FGS reports to learn about other important outcomes.

If you would like to learn more about NCI-IDD, visit: https://idd.nationalcoreindicators.org/

Questions? Email NCI Co-Director Dorothy Hiersteiner at: dhiersteiner@hsri.org

CROSS FAMILY SURVEY COMPARISONS

Person-centered planning requires that people who use services make the decisions about how their service plan is developed and what it includes. The above charts show that one-third of adult family members—the people who are using services—did not help make their service plan; among those who are under age 18, more than 80% did not help make their service plan. In contrast, a majority of the respondents (between 78% and 83%) indicated they helped make their family member’s service plan. This data shows that there is room to improve how service systems support the development of truly person-centered plans.

Family experience with services

This graph (left) shows responses to four questions about family experience with services. Across all surveys, less than 40% of respondents report that services change when their family’s needs change. About half of respondents report that they can always contact support workers when they want and say workers always have the right information and skills to meet family’s needs. Finally, more than one-third of respondents say that case managers do not always listen to their family’s choices and opinions.

High rates of vacancies in the workforce may be contributing to the perception of poorer quality care. These data suggest that state systems need to focus not only on addressing workforce shortages, but also monitoring how shortages impact the outcomes of people who use services.
ADULT FAMILY SURVEY: SAMPLE DETAILS

SAMPLE SIZE
11,989 total respondents

GENDER AND AGE
- 59% Male
- 41% Female
- 0% Other, don’t know, or unclear

34.6 years old (average)

LOCATION
- 22% live in rural area
- 78% live in urban or suburban area

RACE AND ETHNICITY
- 54% White
- 27% Hispanic or Latino
- 10% Asian
- 10% Black/ African American
- 2% Prefer not to say
- 2% Other
- 2% American Indian/Alaska native
- 0% Pacific Islander

DIAGNOSIS
Note: Diagnoses are not mutually exclusive.

- 66% Intellectual disability
- 38% Autism spectrum disorder
- 26% Seizure or other neurological disorder
- 24% Mood or other psychiatric diagnoses
- 17% Cerebral palsy
- 9% Limited/ no vision

SERVICES RECEIVED FROM DD AGENCY
- Financial support: 16%
- In-home: 38%
- Respite care: 24%
- Day/employment supports: 44%
- Transportation: 43%
- Mental/behavioral care: 26%
- Self-direction/FMS: 32%

GUARDIANSHIP
- 65% Has a guardian

PAID SUPPORTS
- 51% said respondent or other family member provides paid supports
ADULT FAMILY SURVEY: OUTCOMES

FAMILY SATISFACTION

44% said they are ALWAYS satisfied overall with the services and supports their family member currently receives

- The highest state rate was 55%
- The lowest state rate was 34%

INFORMATION AND PLANNING

Case manager/service coordinator always listen to family’s choices and opinions

64%

Plan includes all the services and supports family member needs

86%

HEALTH AND SAFETY

75% Family member can always get mental or behavioral health supports when needed

46% Family member can always see primary care provider when needed

61% Family member’s primary care provider always understands family member’s needs related to their disability

ACCESS AND DELIVERY

Family member gets all the services listed in the plan

83%

Family gets the supports and services it needs

73%

Services are always delivered in a way that is respectful of family’s culture

80%

COMMUNITY CONNECTIONS

Family member does things in the community

80%

Family member has friends other than paid support workers or family

58%

WORKFORCE

Family member’s support workers change too often; there is too much “turnover” of support workers

33%

There is always a staff person available to support family member when support is needed

76%

CHOICE AND CONTROL

27% said YES, they, their family member, or someone else in the family chose their family member’s case manager/service coordinator

59% said someone in the family can ALWAYS change their family member’s support workers
CHILD FAMILY SURVEY: SAMPLE DETAILS

SAMPLE SIZE
7,902 total respondents

GENDER AND AGE
71% Male
29% Female
0% Other, don’t know, or unclear
10.6 years old (average)

LOCATION
16% live in rural area
84% live in urban or suburban area

RACE AND ETHNICITY
43% Hispanic or Latino
41% White
14% Asian
8% Black/African American
American Indian/Alaska native
Pacific Islander

DIAGNOSIS
71% Autism spectrum disorder
34% Intellectual disability
14% Seizure/other neurological disorder
12% Mood/other psychiatric diagnoses
9% Down syndrome
8% Cerebral palsy
5% Limited/no vision

SERVICES RECEIVED FROM DD AGENCY
Financial support: 15%
In-home: 35%
Respite care: 29%
Day/employment supports: 8%
Transportation: 6%
Mental/behavioral care: 36%
Self-direction/FMS: 23%

PAID SUPPORTS
41% said respondent or other family member provides paid supports
**CHILD FAMILY SURVEY: OUTCOMES**

**FAMILY SATISFACTION**

36% said they are ALWAYS satisfied overall with the services and supports their child currently receives.

- The highest state rate was 52%.
- The lowest state rate was 28%.

**HEALTH AND SAFETY**

- 39%: Child can get mental or behavioral health supports always when needed.
- 77%: Child can see primary care provider always when needed.
- 60%: Child's primary care provider always understands child's needs related to their disability.

**COMMUNITY CONNECTIONS**

- 71%: Child does things in the community.
- 83%: Child spends time with children who do not have DD.

**CHOICE AND CONTROL**

- 19%: said YES, they or someone else in the family chose their child’s case manager/service coordinator.
- 52%: said someone in the family can ALWAYS change their child’s support workers.

**INFORMATION AND PLANNING**

- Case manager/service coordinator always listen to family’s choices and opinions: 57%
- Plan includes all the services and supports family member needs: 81%

**ACCESS AND DELIVERY**

- Child gets all the services listed in the plan: 81%
- Family gets the supports and services it needs: 64%
- Services are always delivered in a way that is respectful of family’s culture: 80%

**WORKFORCE**

- 37%: Do your child’s support workers change too often? Is there too much “turnover” of support workers?
- 72%: Is there always a staff person available to support your child when support is needed?
FAMILY GUARDIAN SURVEY: SAMPLE DETAILS

SAMPLE SIZE
8,050 total respondents

GENDER AND AGE
60% Male
40% Female
0% Other, don’t know, or unclear
44.8 years old (average)

TYPE OF RESIDENCE
52% Group home
27% Independent home or apartment
14% Institution
4% Foster/host family
0% Homeless
Nursing home
Other

STATES INCLUDED

LOCATION
87% live in urban or suburban area
13% live in rural area

GUARDIANSHIP
71% Has a guardian

RACE AND ETHNICITY
80% White
6% Hispanic or Latino
8% Black/African American
5% Asian
2% Other
2% Prefer not to say

DIAGNOSIS
Note: Diagnoses are not mutually exclusive.

74% Intellectual disability
34% Autism spectrum disorder
33% Mood/other psychiatric diagnosis
26% Seizure/other neurological disorder
16% Cerebral palsy
9% Down syndrome
8% Limited/no vision

SERVICES RECEIVED FROM DD AGENCY

Financial support: 40%
In-home: 45%
Respite care: 59%
Day/employment supports: 76%
Transportation: 52%
Mental/behavioral care: 19%
Self-direction/FMS: 40%
Employment supports: 75%
**FAMILY GUARDIAN SURVEY: OUTCOMES**

**FAMILY SATISFACTION**

44% said they are ALWAYS satisfied overall with the services and supports their family member currently receives.

- The highest state rate was 51%
- The lowest state rate was 23%

**HEALTH AND SAFETY**

- 52% Family member can get mental or behavioral health supports always when needed.
- 73% Family member can see primary care provider always when needed.
- 59% Family member’s primary care provider always understands family member’s needs related to their disability.

**COMMUNITY CONNECTIONS**

- 83% Family member does things in the community.
- 61% Family member has friends other than paid support workers or family.

**INFORMATION AND PLANNING**

- 58% Case manager/service coordinator listens to family’s choices and opinions always.
- 90% Plan includes all the services and supports family member needs.

**ACCESS AND DELIVERY**

- 88% Family member gets all the services listed in the plan.
- 86% Family gets the supports and services it needs.
- 77% Services are always delivered in a way that is respectful of family’s culture.

**COMMUNITY CONNECTIONS**

- 32% said someone in the family can ALWAYS change their family member’s support workers.
- 16% said YES, they, their family member, or someone else in the family chose their family member’s case manager/service coordinator.

**WORKFORCE**

- 43% Do your family member’s support workers change too often? Is there too much “turnover” of support workers?
- 79% Is there always a staff person available to support your family member when support is needed?

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